Status of Orphans and Vulnerable Children in Uganda after Termination of PEPFARS Support Program

Souleymane Barry and Bryan Sayer

Social & Scientific Systems, Inc.

ABSTRACT

Objectives. We examined how 93,398 orphans and vulnerable children (OVCs) fared after the phase-out of support programs funded by the U.S. government's President's Emergency Plan for AIDS Relief (PEPFAR).

Methods. Questionnaires were administered to 735 OVCs and their caregivers selected from lists provided by support services organizations to determine if the children were enrolled in support programs 1 year after the phase out. Project managers from the programs were also interviewed.

Results. The proportion of eligible OVCs previously supported by PEPFAR providers that continued to receive services was 67.2%. Orphans and vulnerable children under 18 were more likely to be enrolled in an OVC program than those 18 and older. Children having one or more specific vulnerabilities were no more likely to be enrolled in a support program than those without.

Conclusions. U.S. government programs exploring avenues for providing sustainable follow-on mechanisms for OVC support may learn from the effective mechanisms implemented by the PEPFAR providers. The most critically vulnerable children (those living in child-headed households, for example) are under-represented in support service programs.

INTRODUCTION

The Uganda HIV/AIDS Sero-Behavioural Survey for 2004–05 estimates that 14% of the under-18 population in Uganda has lost at least one parent and is therefore considered orphaned,[1] and the rate has remained constant since 2001. Based on the 2002 Uganda Population Census and the estimated 3.5% increase in the number of children 0–17 years of age, there were an estimated 2.5 million orphans in Uganda in 2010.[2] The effects of AIDS and a civil war in the northern region of the country since the early 1980s have contributed to the number of orphans.[1]

The population for this study includes not only children who have lost one or both parents, but those who are vulnerable to abuse or harm due to misfortunes such as being HIV positive, living with a chronically ill parent, living with grandparents, or living in a child-headed household.

Types of Support Services Provided to OVCs by PEPFAR Programs

The President's Emergency Plan for AIDS Relief (PEPFAR) is the U.S. government initiative to help those suffering from HIV/AIDS around the world, and the largest by any nation to combat a single disease internationally. From 2004 to 2010, 6 PEPFAR-funded organizations provided a range of support services[3] to 147,500 OVCs in Uganda, including the following:

- Educational/vocational—Schools can provide children with a safe, structured environment, the emotional support and supervision of adults, and the opportunity to learn how to interact with other children and develop social networks.
- Health care—Without appropriate treatment, over 50% of children born HIV-positive die within the first 2 years.
- Food security and nutrition—Malnutrition underlies more than half of the deaths in children under 5 in developing countries.
- Protection—These services include efforts to confront and minimize the stigma and social neglect faced by OVCs, as well as abuse and exploitation that include trafficking and theft of inherited property.
- Psychosocial support—High levels of psychological distress found in AIDS orphans suggest that material support alone is not sufficient for these children.[4]

Motivation for this Study

Between June and September of 2010, these PEPFAR OVC support projects were phased out after 5 years of providing support. The authors of this paper—the Uganda Monitoring and Evaluation of Emergency Plan Progress (MEEPP) project team—designed a study to understand what happened to the many thousands of OVCs previously supported by PEPFAR providers.

The key questions addressed by the study were:

1. Did OVCs continue to receive external support (i.e., support not provided by the government of Uganda) after the close-out of their PEPFAR projects?
2. How did characteristics such as age and vulnerability profile affect their likelihood to continue to receive external assistance?
3. What specific measures taken by PEPFAR providers facilitated continued assistance to OVCs?

METHODS

Sample Design

The study involved two parts: administering questionnaires to OVCs and their caregivers, and interviewing project managers of the discontinued PEPFAR programs.

Six primary support service organizations, plus several subcontractors, served OVCs in a total of 95 districts in Uganda from 2004 to 2010. Using lists of OVCs submitted to MEEPP by 5 of these service providers, a pool of 93,398 potential study participants (representing 63% of the 147,501 OVCs reported to MEEPP for the 2010 PEPFAR Annual Program Results Report) was initially identified[a]. Since providers were allowed to structure their support programs individually (thus programs varied in the delivery of services by provider), the study team stratified the sample by provider and selected 2 districts for each of 5 providers who worked in multiple districts, and a single district for the one provider who worked only in a single district. Next, 180 OVCs were selected randomly from the districts for each provider, split evenly across districts. One provider (with 2,837 children) was unable to supply location information for any OVCs. Ultimately, 900 children in 9 districts were sampled from the 5 providers able to provide location information for the OVCs served by them or their subcontractors.

Interviews were conducted with the managers of 8 PEPFAR programs operated by 6 of the support service organizations and 2 subcontractors of one of the 6 organizations.

Response Rate

Of the 900 OVCs sampled having location information, 728 were located and interviewed, and an additional 7 were determined to be deceased, for a total response rate of 81.7% (N=735). Questionnaires were administered to both the OVC and caregiver for the 728, and the caregiver only for the 7 decedents.

Implementation

Interviewers administered questionnaires containing closed- and open-ended questions to the sample of 735 OVCs and their caregivers. All interviewers received a 1-day orientation on the questionnaire, including a session to validate the translation of specific questions into local languages.

The interviewers also spoke with project managers from 8 programs to briefly explore the model of assistance provided to OVCs, and their perspective on continuity of services. The study team used annual and semi-annual program reports submitted to PEPFAR by the providers as an additional source of information.[5] The data collection process was coordinated by two MEEPP staff located in Kampala, Uganda. Five 4-person teams (which each included former or current staff of the respective providers) plus a full-time field coordinator collected the data.

Data Processing and Analysis

All questionnaires were reviewed by the field coordinator for completeness before submission for data entry. Two MEEPP program assistants were responsible for entering the data into a web-based system, using double entry procedures. The study team summarized the findings across PEPFAR providers and conducted tests of significance. One statistician and one programmer from the MEEPP project contractor provided data analysis support.

[a] The majority of the discrepancy between the number of OVCs reported served (147,501) and the number obtained on the lists (93,398) was due to a single provider who used a number of subcontractors. Two of the subcontractors were not able to provide lists and location information for OVCs served by them.

All estimates are weighted, and variances are calculated using stratification (provider) and clustering (district). Sampling weights include the probability of selection at the district and individual level, and non-response adjustment. The initial sample design assumed relatively low design effects of about 1.2, which turned out to be a significant under-estimate. Observed design effects varied depending on the specific population and estimate. Average per provider design effects ranged from a low of 0.4 to a high of 11. All estimation was done in SUDAAN version 10, and design effects are based on definition 2 in the SUDAAN language manual[6], which measures the inflation of variance due to stratification (or blocking), clustering, and unequal weighting. This measure assumes that subgroup sample sizes are fixed. Since the number of OVCs for each provider and district is known, we believe this is the most appropriate definition to use for design effects.

RESULTS

The overall proportion of eligible OVCs previously supported by PEPFAR providers that continued to receive any service after the end of the PEPFAR projects was 68.1%. Orphans and vulnerable children under 18 (as of the date of interview) were more likely to have received services from an OVC program than those 18 and older. Children determined to have at least one of a specified list of vulnerabilities (see Table 2) were no more likely to have received services from a support program than children without the vulnerability. However, children with any specified vulnerability were more likely to have received a service within the past 1 or 2 months than children with none of the specified vulnerabilities.

Enrollment in an OVC Program after the Termination of the PEPFAR Projects

Table 1 shows the percentage of OVCs who received different types of services by age after the termination of the PEPFAR projects, defined as enrollment in an OVC program. Results obtained from the 5 responding providers indicated that 68.1% of all OVCs were enrolled in an OVC program in June and July of 2011, about 1 year after the termination of their PEPFAR projects.[b]

The most common services provided to OVCs by these programs were psychological support, education, and health care.

[b] About 25% of OVCs who were not enrolled in a program were 18 and older and were, in principle, not eligible for services. However, a relatively high number of OVCs 18 and older who were in need of continued support continued to be enrolled in a program as agreed upon with the PEPFAR OVC Technical Working Group.

TABLE 1—Percentage of OVCs enrolled in support programs after the phase-out of PEPFAR programs, and types of services received

Enrollment Status and Services Received	All OVCs	OVCs under 18	OVCs 18 and older	Difference (under 18 – 18 and older)	p-value difference
Enrollment Status					
Currently enrolled in OVC program	68.1%	73.3%	31.5%	41.8	0.000
Services Received					
Any core OVC service received in past month	38.7%	40.1%	23.0%	17.2	0.031
Psychosocial support	25.2%	27.2%	11.5%	15.7	0.005
Educational/vocational support	17.6%	17.6%	17.7%	(0.1)	0.991
Health care	12.3%	12.2%	13.2%	(1.0)	0.872
Economic strengthening	5.2%	5.6%	2.4%	3.2	0.176
Food security and nutrition	3.7%	3.9%	2.9%	1.0	0.685
Care and support	2.5%	2.6%	1.9%	0.7	0.529
Protection	0.7%	0.8%	0.0%	0.8	0.187
Legal support	0.2%	0.1%	2.4%	(2.3)	0.143

Effects of Age and Vulnerability Profile on Continued Support

Age

As shown in Table 1, orphans and vulnerable children under 18 were more likely to be enrolled in an OVC program than those 18 and older (72.4% versus 30.9%). At the 5% level, the only significant difference in the type of services received by OVCs in the two age groups was for psychological support: OVCs under 18 were more than twice as likely as those 18 and over to have received psychological support (26.2% versus 11.0%).

Vulnerability Profile

Table 2 shows that 64.7% of the study group OVCs were coping with at least one specified vulnerability (not mutually exclusive except for loss of one or both parents) such as being HIV positive, living with a chronically ill parent, living with grandparents, living in a child-headed household, or having lost one or both parents to HIV. Even though about 43% of the children in the study population had lost one or both parents to HIV, less than 2% of them were reported themselves to be HIV positive. Table 2 also shows that almost all HIV-positive OVCs continued receiving services from an OVC program (92.9%), an encouraging result. Unfortunately, it also shows that the lowest enrollment rate was among OVCs living in child-headed households (42.8%), one of the most vulnerable groups. A similar trend was observed in a 2009 population-based household survey[7] conducted by the Population Council: the most critically vulnerable children were not receiving the level of skills training, start-up capital, nutritional support, and counseling as the study population in general.

TABLE 2—Percentage of OVCs with specified vulnerabilities and percentage receiving services

Vulnerability	Percentage of OVCs	Percentage with specified vulnerability enrolled in a program
With any specified vulnerability	64.7%	74.3%
With two or more vulnerabilities	6.8%	73.5%
Specified Vulnerabilities		
Lost one parent to HIV	27.9%	74.2%
Lost two parents to HIV	16.1%	67.6%
Living with grandparents	15.2%	80.9%
Living with chronically ill parent	10.4%	75.9%
HIV positive	1.4%	92.9%
Living in child-headed household	0.9%	42.8%

Although the data suggest that OVCs with any specified vulnerability are no more likely to have received services from an OVC program than OVCs with no vulnerability, those with a vulnerability were more likely to indicate receiving services during the month of the survey, or the month immediately preceding the survey, than those with no specified vulnerability, as shown in Table 3. Although OVCs with a specified vulnerability are more likely to receive each of the specified services, only economic strengthening is significant at the 5% level, while protection or counseling services are almost significant at the 5% level.

TABLE 3—Percentage of OVCs receiving specified services within 2 months of the survey, by vulnerability status

Measure	All OVCs	OVCs with no specified vulnerability	OVCs with any specified vulnerability	Difference (Any vulnerability – No vulnerability)	p-value of difference
Enrollment Status					
Currently enrolled in OVC program	68.2%	57.0%	74.3%	17.3	0.200
Services Received					
Any core OVC service received in past month	39.0%	29.2%	44.3%	15.0	0.107
Psychological support	25.4%	17.6%	29.7%	4.6	0.057
Educational/vocational support	17.9%	14.8%	19.6%	4.8	0.347
Health care	12.2%	10.7%	13.0%	2.3	0.718
Economic strengthening	5.1%	2.9%	6.4%	3.5	0.032
Food security and nutrition	3.7%	1.9%	4.7%	2.9	0.272
Care and support	2.7%	2.4%	2.9%	0.6	0.554
Protection	0.7%	0.2%	0.9%	0.6	0.057
Legal support	0.4%	0.2%	0.5%	0.2	0.318

Facilitating Graduation from External Assistance

The goal of OVC support services is to help vulnerable children and adolescents grow and develop into healthy, well-adjusted, and productive members of society. When reporting effective measures for empowering OVCs, PEPFAR providers reported occupational training, income-generating activities, and provision of start-up equipment, materials, and funds. Similarly, in survey responses from caregivers of OVCs regarding the type of support they would like to receive in order to better support the OVCs in their care, many mentioned support for economic empowerment. The dominant items cited were startup capital and small loans for income-generating activities, vocational training, and assistance in acquiring necessary implements such as sewing machines and tools to carry out projects.

Measures that Affected Continued Assistance to OVCs

The interviews with providers and their subcontractors revealed selected measures that facilitated continued support, as well as challenges that prevented continued support to OVCs.

Measures that Facilitated Continued Support to OVCs

Project managers from 8 PEPFAR programs were interviewed. Results show that staff from 4 of the programs implemented measures to ensure continued support to eligible OVCs: one provided continued support to 3,871 OVCs; one provided direct services to selected OVCs; one transferred 54 OVCs to a youth center; and one enrolled caregivers in a loan program.

Generally speaking, support to OVCs as a core business combined with a diversified funding base, and linkages with community-based organizations were positive influences on continued enrollment of OVCs according to interviews of program managers and analysis of the narratives provided by providers in PEPFAR annual and semi-annual reports. The measures reported by PEPFAR providers for sustaining support to or empowering eligible OVCs include:

- Working with districts during project planning, implementation, and close-out
- Developing a phase-out strategy including shifting selected OVCs to programs funded by other donors and intergovernmental agencies
- Capacity building of community-based organizations
- Participating in income-generating activities
- Providing vocational training and start-up equipment, materials, and funds
- Offering leadership training of community leaders
- Providing skills enhancement programs for caregivers and women

Reasons for Discontinuing Support to OVCs

One of the 5 participating providers had a particularly low follow-on enrollment rate for the children in its program: about 4% compared to between 74% and 99% for the other 4 providers. This low rate may be explained in part by the lack of established relationships with community-based organizations offering services to OVCs. The organization had opted to work mainly with the government bodies in charge of vulnerable children and provided direct support to OVCs and their caregivers. The comprehensive support to OVCs provided over many years by this organization had gradually displaced other providers. So, when PEPFAR terminated support to the program, and it ceased providing services, nearly all the OVCs it had served no longer received services from any source.

Three providers cited shortage of resources and a lack of economic strengthening as the main reasons for discontinuing assistance to OVCs. Reasons for not transferring OVCs to other organizations included the assumption that collaborating providers would continue to provide support after the termination of their particular project, and the belief that other OVC organizations were already operating at full capacity so had no space for additional OVCs.

DISCUSSION

The PEPFAR program has been effective in establishing measures to ensure continuity of services to OVCs following the termination of its support activities. The PEPFAR providers that developed structured and sustained linkages with community-based organizations and built on a diversified funding base were more likely to ensure continued support to eligible OVCs. However, the survey did not assess the quality of continued services received by OVCs through community-based organizations.

In general, OVCs with specific vulnerabilities (HIV positive, orphans to HIV/AIDS, living with ill parents, living with grandparents, or in child-headed households), were no more likely to be enrolled in an OVC program than other OVCs. However, once enrolled, the OVCs with the vulnerabilities describe above were more likely to receive support for selected services. Almost all HIV-positive OVCs were enrolled for continued support.

Limitations

The observed design effects for provider-specific comparisons are larger than anticipated, and some comparisons (not shown here) that appear to be significant actually lack statistical significance. Comparisons made here may also be impacted by the large design effects, thus further investigation of the design effects of the sample design—and their impact on significance tests—is warranted.

As there are potentially a large number of OVCs not listed on the registry from which the sample was drawn, care should be used in extending these conclusions beyond the population of studied OVCs. Since many of the unaccounted for OVCs appear to have been served by subcontractors to the 6 providers, it is possible that their experiences differ greatly from the experience of OVCs in the listing, as outcomes may vary by provider and subcontractor.

Conclusions

Any U.S. government programs exploring avenues for providing sustainable follow-on mechanisms for OVC support may learn from the effective mechanisms implemented by the PEPFAR providers. The findings, conclusions, and recommendations should be thoroughly discussed with USAID and others providing programs to support OVCs.

This study showed that relatively lower levels of support were provided to the most vulnerable OVCs (those living in child-headed households). Improved validation of the selection of OVCs, and appropriate programmatic measures taken by policy makers and OVC program managers would help ensure that the most vulnerable receive appropriate support. A vulnerability index specific to the Ugandan context recently developed by MEEPP staff should help shed light on the complicated issue of OVC selection.

Additional qualitative studies are recommended to understand the quality of services received by OVCs through community-based organizations and validate the reasons for extreme variation in level of coverage of OVCs in selected areas. This study also highlights the importance of tracking services to OVCs, especially novel strategies designed for empowering households with income-generating activities or other means (rather than providing handouts that may not translate into actual support to OVCs).

Acknowledgments

This study and report are made possible by the generous support of the American people through the United States Agency for International Development (USAID) and PEPFAR under the terms of USAID/SSS Contract No. AID-617-C-10-00008. The contents do not necessarily reflect the views of USAID or PEPFAR. The views expressed here are the views of the authors and not necessarily the views of Social & Scientific Systems, Inc. The authors would like to thank Barbara Amuron, Vincent Owarwo, Sarah Kyokusingura,

Margaret Juliana Mugerwa, and Sarah Nabukera for their contributions to the study; and Janette Walters for her editorial support.

REFERENCES

[1] Uganda Ministry of Health and ORC Macro. *Uganda HIV/AIDS Sero-behavioural Survey 2004-2005*. Calverton, Maryland, USA: ORC Macro; 2006.

[2] Uganda Bureau of Statistics. *Uganda Population and Housing Census Analytical Report*. Kampala, Uganda: Uganda Bureau of Statistics; 2006.

[3] The President's Emergency Plan for AID Relief, Office of the Global AIDS Coordinator. *Orphans and Other Vulnerable Children Programming Guidance for United States Government In-Country Staff and Implementing Partners*. Washington, DC: PEPFAR; 2006.

[4] Atwine B, Cantor-Graae E, Bajunirwe F. Psychological distress among AIDS orphans in rural Uganda. *Soc Sci Med*. 2005;61(3):555-64.

[5] MEEPP. *Uganda Annual and Semi-Annual Program Results Reports 2008*. https://meepp.or.ug. Accessed September–October 2011.

[6] Research Triangle Institute. *SUDAAN Language Manual, Release 10.0*. Research Triangle Park,NC: Research Triangle Institute; 2008.

[7] Kalibala S, Schenk KD, Weiss DC, Elson L. Examining dimensions of vulnerability among children in Uganda. *Psychol Health Med*. 2012;17(3):295-310.